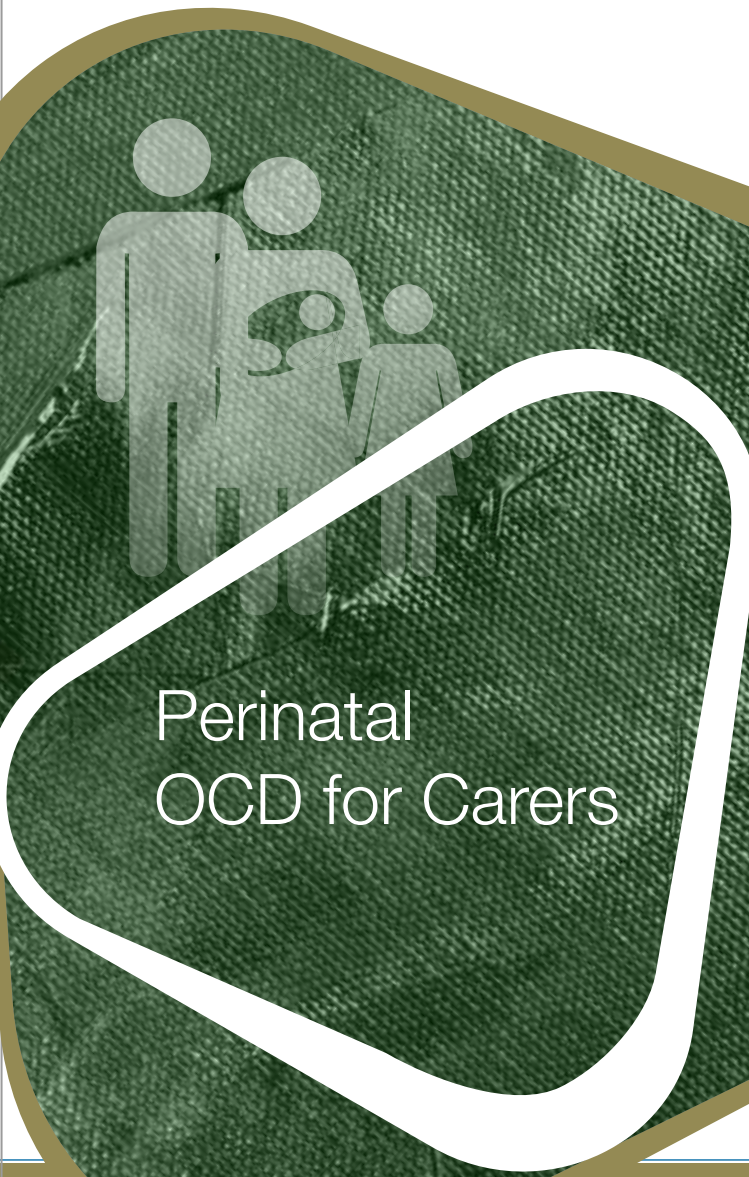
HSE NATIONAL PROGRAMME

Specialist Perinatal

MENTAL HEALTH SERVICES



Perinatal OCD for Carers

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Disclaimer: This webpage provides information, not advice. You should read our full disclaimer before reading further.

This leaflet is for the partners, family and friends of any woman with Perinatal OCD.

The leaflet describes:

- What Perinatal OCD is.
- The treatments available.
- How partners, family and friends can support someone with OCD during pregnancy and the first year after birth.
- How a partner or relative can get support for themselves.
- Further sources of help, information and support.
- How to improve communication between a mother with Perinatal OCD, her carers and mental health professionals.

The checklists at the end aim to help families, and health professionals, to communicate well when a woman has Perinatal OCD.

Perinatal OCD

Obsessive Compulsive Disorder (OCD) is a fairly common mental health problem. It can affect men and women at any time of life (NICE OCD) [3]. It is called Perinatal OCD when a woman develops OCD during pregnancy or after birth - the perinatal period. Perinatal OCD affects at least 2 in every 100 women [1].

Perinatal OCD has three main parts:

1. **Obsessions** - frequent unpleasant thoughts, images, urges or doubts.

2. **Anxiety** - distress caused by these unpleasant thoughts.

3. **Compulsions** – behaviours (e.g. washing of hands) or mental acts (e.g. counting) that the person keeps repeating, to try to reduce their anxiety or to prevent bad things from happening.

In Perinatal OCD, symptoms are often (but not always) focussed on the baby. These could be:

- Intense fear that the baby will be contaminated with germs, dirt or poison, and will die as a result. The mother may go to great lengths to prevent contamination by excessive hand-washing or sterilising, or not using public nappy changing facilities.
- Thoughts or images (pictures in their mind) of the baby coming to harm e.g. cot death. The mother finds herself repeatedly checking on the baby's breathing during the night.
- Thoughts or images of harming the baby, either accidentally or deliberately. Sometimes these thoughts can be sexual or violent. Women often feel deeply distressed and ashamed by these thoughts. We know that people with OCD do not become violent or act on these thoughts. But, as a result of them, a mother may start to avoid sharp objects,

like kitchen knives, or situations such as nappy changing.

- Worrying too much about doing things or not doing things in a particular way e.g. not sterilising the baby's bottles correctly.
- Asking for reassurance again and again from others – for example, about whether something is clean enough.

It is very common for a mother to have occasional unpleasant thoughts about her baby being harmed [2]. These can be frightening for anyone. But, if you have Perinatal OCD, these thoughts occur so often, and are so upsetting, that it becomes difficult to do everyday tasks. These thoughts can also lead to a woman thinking she is a bad mum and to become depressed. This is not only difficult for the mother, it can also be hard for a supportive partner or family member to see. *For more information see our leaflet on* ***Perinatal OCD***.

Treatment

Perinatal OCD is very treatable [3-7]. The GP, midwife and public health nurse can advise you and your partner/ relative about what kind of help to access.

The two main treatments for Perinatal OCD are:

- **Cognitive Behavioural Therapy** (CBT) - a talking therapy
- **Antidepressant Medication** – a woman can use these medications even when she is pregnant or breastfeeding. The GP or psychiatrist can discuss the risks and benefits of medication in the individual case.

CBT and medication can be used alone or together [3-6].

For more information see our leaflet on

- *Mental health in pregnancy (this has information about weighing up the risks and benefits of medication in pregnancy and breastfeeding)*

- *OCD (this has details of CBT for OCD)*

After making a diagnosis, or if the diagnosis is unclear, the GP may refer your partner/relative to another service. This could be:

Psychological (talking) therapies services can offer CBT for women with perinatal OCD.

Perinatal Mental Health Service.

For more severe Perinatal OCD which has not responded to treatment by the GP and Psychological Therapies Services, your partner/relative may be referred to a Specialist Perinatal Mental Health Service. Midwives, mental health midwives, obstetricians, and other professionals can also refer you. Your partner/relative may see a psychiatrist, psychologist, nurse or mental health midwife in the Perinatal Mental Health Service.

In Ireland all maternity units/hospitals should have access to perinatal mental health services through mental health midwives. Specific perinatal psychiatrists work from the larger hub sites based in the Dublin maternity hospitals and also in the maternity units/hospitals in Limerick, Cork and Galway. These services can be accessed through your GP or midwife at the booking clinic. Mental health midwives in the smaller spoke hospital sites are a point of contact for additional mental health support, including access to liaison psychiatric services who are also linked to the psychiatric teams in specialist hub sites. For more information, see our leaflet on Perinatal Mental Health Services.

How partners, relatives and friends can help

There are lots of things you can do to help your partner/ relative. These include:

Practical support

- Help out around the house e.g. cook healthy meals, manage children's bedtimes, share the housework, make sure there are small healthy snacks around.
- Encourage times for rest. OCD can be mentally exhausting, on top of the demands of being a new mother.
- Agree when people will visit in advance. Space out visits so they are not too tiring.
- Help your partner/ relative to understand that they **can** to say 'no' to requests.

Emotional support

- People need different types of support at different times. You will know, from experience, what helps your partner/relative. For example, some people like affection at times of stress, whereas others prefer to be left alone until they feel calmer.
- Perinatal OCD can make a mum question her parenting ability. Encourage her and remind her of what she is doing well. Help her to feel that she is doing the best she can.
- When she has OCD-free moments, use these as beacons of hope and praise her.
- If she feels worthless, or that she can't do anything, work with her to build back up her self-esteem.
- Give your partner/relative hope –remind her that she can recover. Help her to read some success stories. (See the Maternal OCD website for examples).

Recovery focused support

- Notice when your partner/relative might be avoiding something because of her thoughts - but don't criticise her for not trying. Instead, encourage her to make time each day for her therapy homework.
- Find local support groups that she can go to - either by herself or with you.
- Work together to understand what helps your partner/relative through an OCD moment so you can help her control her own recovery.
- During therapy, support her to challenge her thoughts and beliefs and see OCD thoughts for what they are – bullying and unreasonable.
- Regularly check in with your partner to see what could help, or not help
- Understand what you need to do. Sometimes this means **not** reassuring your partner/relative - because we know that this does not help. You may have to support her to **not** ask for reassurance.

Increase your understanding of OCD

- Find out as much as you can about OCD and how treatment works. This can help you support your partner/relative to make changes. It can also help you understand her beliefs and behaviour, which can seem quite irrational.
- Encourage her to seek help – you are not a therapist and, whilst you can help your partner/relative in recovery, she will need professional help.
- Understand how OCD can affect a mum - and the process of getting better.
- Remember - Perinatal OCD and Postnatal Depression **are** different.
- Your partner/relative may seem to be very rigid, stuck in unhelpful ways of thinking and doing things. This is common in OCD and it can feel overwhelming. Understanding this will help you both to get through the process of recovery.

- Having OCD can mean that a woman finds it difficult to be intimate with her partner. Don't take this personally or as a sign that she does not care about you.
- Your partner/relative will have normal worries which are common for all parents– not all worries are caused by OCD!

Communication

- Keep listening and talking.
- It can be very frustrating to see your partner/relative in the grip of OCD. If you feel this, try to reassure her that it's the OCD you are frustrated with, not her. Remember that with help and support she can get through this.
- Try to agree together to have some conversations that are **not** about OCD.
- Be aware of body language (yours and hers). For example, you might start to notice a particular posture or look (e.g. standing still and staring) as a sign that your partner/relative is experiencing obsessional thoughts. She may misinterpret the way you look at her as meaning she hasn't cleaned or checked something properly.
- Some women find it helpful to choose a simple word they can say to a friend or family member to let them know they are feeling distressed and need support when they are in a social situation.

Making sure you also get help and support

It can be stressful supporting a woman with perinatal OCD, especially if you are also the main carer for a baby and other children. It is important that you look after yourself as well.

Understand common feelings

As a partner/carer at times you may feel:

- Frustrated and helpless.
- Shocked at, disappointed or angry with your partner/relative.
- Scared and/or ashamed about admitting there is a problem.
- Scared to seek help, maybe because you fear the baby will be taken away.
- Worried about the effect of the illness on the baby.
- The baby is to blame.
- Worried about the responsibility of caring for the woman and/or baby, and scared to leave them alone.
- Exhausted by caring for the mother, baby and other children.
- Resentful that your needs have been pushed to one side.

These are all common feelings. It is important that you have somewhere you can talk about how you feel and get support for yourself.

Look after yourself

It can be stressful and exhausting (for you and other family members) to look after someone with Perinatal OCD. You need to take good care of yourself. There are many ways to do this:

- Get some rest when you can.
- Try to get regular exercise, meals and sleep.
- Don't be afraid to ask for help. Ask friends, family members or your GP for support.
- Explain to your employer why you may need extra time off.
- Share your worries with trusted friends or family members.
- Look after your own health. See your doctor if you are feeling exhausted or depressed.
- As the OCD improves, try to have some fun with your partner. Get a baby-sitter or go out together.
- Do not feel that you are solely responsible for your partner/relative's recovery. You are an important part of this, but she also needs help from professionals - who should support the whole family.

Working in partnership with doctors and other professionals

Good communication between a woman with Perinatal OCD, her partner/carer, her doctor and the other professionals involved in her care is very important. This can take time and effort. There are many questions you may want to ask. The following checklist includes some suggestions.

Useful questions to ask the psychiatrist or other professionals:

- [ ] **Is the diagnosis Perinatal OCD?**

- [ ] **Is there any other diagnosis as well, for example Depression?**

- [ ] **Is medication being prescribed?**
  - Is this safe to use in pregnancy?
  - Will she be able to breastfeed with the medication?
  - How long might she need to stay on the medication after recovery?

- [ ] **Is my partner/relative being offered Psychological therapies?**
  - When will this start?
  - How many sessions will she need?
  - Can you tell me how it works?

- [ ] **Are there other things we can do to help ourselves?**

- [ ] **What can we expect in the near future and over time?**

- [ ] **How often should we see you and the other professionals?**
  - Will anyone visit us at home?

- [ ] **Who is our main contact for guidance and advice?**

- [ ] **What else is in my partner/relative's care plan?**

- [ ] **Are there any other organisations or services that can help?**

- [ ] **Is there anything we can change at home to make things easier or safer?**
- [ ] **Will the baby be affected?**
- [ ] **Does this mean we should not have another baby?**
- [ ] **Who can we contact and what should we do in an emergency**?

If your partner/relative needs another appointment, remember to arrange this before you leave. Regular, well prepared visits to the doctor will help to get the best care for both of you, and the baby.

Preparing for follow-up appointments

Before your visit:

- Keep track of changes in your partner/relative's symptoms and the impact these have on her daily activities. Try to notice any problems with medication. Keep note of any concerns or questions that have cropped up since your last visit. It may help to write these down.
- It may be helpful to sit together and decide what concerns you both want to discuss with the doctor. Writing these down means that you do not have to worry about remembering them. You can be sure to talk about the things that matter most. These might include questions about:

  - changes in symptoms or behaviour.
  - side-effects of medications.
  - general health.
  - your own health.
  - your baby's health.
  - help needed.

During your visit:

- If you do not understand something, ask questions until you do. Don't be afraid to speak up.
- Take notes during the visit. At the end, look over your notes and tell the doctor what you understood. This gives the doctor a chance to correct any misunderstandings, or to repeat anything that has been missed.

Tips for dealing with doctors

Doctors can be reluctant to discuss a woman's diagnosis or treatment with her partner/relative because of their duty of confidentiality to the patient. However, if your partner/relative gives consent there should be no problem with this. Doctors usually appreciate the involvement of partners / carers. You can often provide useful information as you will notice changes and can report on how she is doing. The doctor will also understand how important your support and practical help is.

Although many professionals will be happy to see you together, it may be important for a woman to be seen on her own too. However close you are, she may put on a brave face in front of you. She needs a chance to speak to her doctor and the other professionals involved in her care on her own. This will give her a chance to openly discuss her feelings about the illness and its impact on her pregnancy, baby and other family members. You can ask to come in for part of the appointment with the doctor or other professionals. ***You can also ask for some time to talk to the doctor on your own if needed.***

For professionals

As a professional working with women with Perinatal OCD and their carers, we hope that these suggestions are helpful. Communication with the whole family is essential when supporting a woman with Perinatal OCD. Working together will help you to understand a mother in her family context. Her partner and family will know more about her, and the differences between when she well and unwell, than anyone else. Be mindful of the fact that partners and carers may be physically and emotionally exhausted if they are looking after an unwell mother as well as a baby and other children.

The following is a guide to good practice in working with families affected by Perinatal OCD:

At the first assessment do you?

- ☐ Try to see the woman and her partner/family member separately as well as together?
- ☐ Ask about their home environment - their environment could be important?
- ☐ Do you allow yourself enough time to:
- ☐ Listen and ask questions of both the woman and her partner/family member?
- ☐ Take a thorough history?
- ☐ Leave time for questions and discussion?
- ☐ Explain how you made the diagnosis?
- ☐ Talk about the prognosis and recovery?

When discussing care and treatment, do you?

- ☐ Discuss possible treatments, including medication and psychological (talking) therapies?
- ☐ Talk about the possible side-effects of medications?
- ☐ Talk about the safety of medication in pregnancy and breastfeeding?
- ☐ Spend time asking about the partner/family member's health – physical and emotional?
- ☐ Discuss how to meet the health needs of the woman, the baby, the partner and other carers?
- ☐ Give information about organisations which can offer information and support, such as Maternal OCD?
- ☐ Make sure families know who to contact for help in working hours and in an emergency out of hours?

Further information/ online resources

Further help

Maternal OCD: A charity set up by mothers who have recovered from Perinatal OCD. They can provide support via email, Twitter and Skype. For further details please contact: https://maternalocd.org/

OCD Action: A charity providing information about OCD, a dedicated OCD helpline, email support and advocacy service. Contact details: https://ocdaction.org.uk/

HSE's Your Mental Health (https://www2.hse.ie/mental-health/). Find advice, information and support services for mental health and wellbeing.

MyChild (https://www2.hse.ie/my-child/). Your guide to pregnancy, baby and toddler health. Trusted information from experts and Health services and support.

Dadvice (https://healthyfamilies.beyondblue.org.au/pregnancy-and-new-parents/dadvice-for-new-dads). Tips for supporting yourself and your family.

Dadpad (https://thedadpad.co.uk/). It's the essential guide for new dads, developed with the NHS.

Psychological Society of Ireland (https://www.psychologicalsociety.ie/). This online voluntary directory is to help you find a psychologist who is recognised by the Psychological Society of Ireland (PSI) as being a Chartered Member of the Society.

Counselling in Primary Care CIPC.ie (https://www.hse.ie/eng/services/list/4/mental-health-services/counsellingpc/).

Tusla community based supports – family resource centres. (www.tusla.ie/services/family-community-support/family-resource-centres/).

MABS : https://www.mabs.ie/en/ MABS Helpline 0761 07 2000 Mon - Fri, 9am - 8pm

MABS is the State's money advice service, guiding people through dealing with problem debt.

Citizen's Information: www.citizeninformation.ie. Your rights and entitlements from the citizen's information board.

Further Reading

The following books all include chapters about how family and friends can help:

- Break Free from OCD - Dr Fiona Challacombe, Dr Victoria Bream Oldfield and Prof Paul Salkovskis ISBN 978-0-09-193969-4.
- Overcoming Obsessive Compulsive Disorder – David Veale & Rob Willson ISBN 1-84119-936-2
- Dropping the Baby and Other Scary Thoughts – Karen Kleiman and Amy Wenzel ISBN 978-1-138-87271.

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Credits

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You must therefore obtain the relevant professional or specialist advice before taking, or refraining from, any action based on the information in this leaflet.

If you have questions about any medical matter, you should consult your doctor or other professional healthcare provider without delay.

If you think you are experiencing any medical condition you should seek immediate medical attention from a doctor or other professional healthcare provider.

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